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Methods of legitimation: How ethics committees decide which reasons count in public policy decision-making

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ABSTRACT

In recent years, liberal democratic societies have struggled with the question of how best to balance expertise and democratic participation in the regulation of emerging technologies. This study aims to explain how national deliberative ethics committees handle the practical tension between scientific expertise, ethical expertise, expert patient input, and lay public input by explaining two institutions' processes for determining the legitimacy or illegitimacy of reasons in public policy decision-making: that of the United Kingdom's Human Fertilisation and Embryology Authority (HFEA) and the United States' American Society for Reproductive Medicine (ASRM). The articulation of these 'methods of legitimation' draws on 13 in-depth interviews with HFEA and ASRM members and staff conducted in January and February 2012 in London and over Skype, as well as observation of an HFEA deliberation. This study finds that these two institutions employ different methods in rendering certain arguments legitimate and others illegitimate: while the HFEA attempts to 'balance' competing reasons but ultimately legitimizes arguments based on health and welfare concerns, the ASRM seeks to 'filter' out arguments that challenge reproductive autonomy. The notably different structures and missions of each institution may explain these divergent approaches, as may what Sheila Jasanoff (2005) terms the distinctive 'civic epistemologies' of the US and the UK. Significantly for policy makers designing such deliberative committees, each method differs substantially from that explicitly or implicitly endorsed by the institution.

1. Expertise and reasons: a tension in practice

Until recently, decisions regarding science and technology policy in democratic societies were frequently made by scientific advisory panels, which tended to operate under what political scientist Alfred Moore (2011) has called a "technocratic model of expert authority" (p. 10). This pattern of decision-making by an elite class of scientific experts was often justified by traditional public understanding of science theories that posited an ignorant, incompetent, and irrational public that hampers the progress of science (Jasanoff, 2005). This technical model of scientific governance focused most heavily on quantitative calculations of risk and benefits to health and safety, suggesting "a presumption of ethical unity on the prioritization of health and welfare" (Moore, 2010b, p. 201). Yet, as perceptions of the public's capacity to understand and contribute to the dialogue on the proper role of science and technology in society improved, scientists' and science advisors' privileged role in the policy-making process came under attack (Wynne, 2006; Abelson et al., 2003). Members of the lay public, although still largely drawn from an elite class of academics and lobbyists, began to question why scientific experts, simply because of their *technical* expertise, should have the exclusive authority to say what the role of science and technology *ought* to be in pluralistic, democratic societies (Kelly, 2003).

One response to these critiques in many technologically-advanced, democratic societies has been the institution of national deliberative ethics committees, particularly in the context of health care and biotechnology. By 'ethics committee' throughout this paper, I refer to what Schicktanz and Dusche (2011) term 'macro level' institutions, as distinguished from 'local level' institutions, like hospital ethics committees, or 'meso level' institutions, like research ethics committees, neither of which are considered here (p. 142). I define this type of macro level ethics committee more specifically as a deliberative body tasked with making ethical judgments in a specific (health) policy area for a particular society. Although the composition and process of these

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committees varies immensely, they all promise to bring larger social and public concerns to bear upon rapidly advancing and emerging technologies. Yet these ethics committees, presented as an answer to the un-democratic elements of authority based upon *technical* expertise, inadvertently created a new challenge in instituting expert authority based upon *ethical* expertise.

The crux of the controversy appears to lie in the process by which ethics committee members assume the authority to categorize reasons or arguments that they assess within their deliberative space as either 'appropriate' or 'inappropriate'. Moore (2010a) has described this move as the practice of making "some kinds of concerns appear *legitimately* ethical" while making others appear to be "merely political or transient matters of public concern," such that the latter concerns are rejected or de-emphasized (p. 727, emphasis added). Similarly, as part of their analogy of "the moral economy of science," Alison Harvey and Brian Salter (2012) describe this process as "regulating the currency of the moral economy" by configuring "diverse value positions … as legal or illegal tender" and setting the "exchange rate for trading different values" (pp. 194–198). Yet again, as these new ethical experts began to dominate debates over values, champions of public values and patient voices pushed back, fueling the patient and public involvement (PPI) movement so prominent in UK governance of health care today (Florin and Dixon, 2004; Hogg, 2007). Although the justifications for PPI are many and still quite muddled, one common explanation is that citizens should have a say in which values drive the regulation of science and technology.

As more and more individuals sit down around the metaphorical, and often literal, table – the scientist, the bioethicist, the expert patient, and the lay member of the public – a tension arises concerning what it means to make a legitimate public decision: who decides which reasons ought to be voiced and carry force in the public sphere of pluralistic, democratic societies? Here I rely on Sheila Jasanoff's vague but fitting definition of democracy as "not a singular form of life but a common human urge to self-rule that finds expression in many different institutional and cultural arrangements" (2005, p. 290). I focus on democratic societies because, as Caroline Mullen (2008) notes, there are two "senses of defensibility in decisions on ethics" in this particular political context: whether the decisions are representative of public values and perspectives and whether the decisions withstand ethical scrutiny, which she aptly identifies as a tension between 'representation' and 'reason'. This deliberative decision-making plays out in practice a long line of theoretical controversies concerning which reasons ought to carry weight in the public sphere: John Rawls' (1997) notion of "public reasons," Robert Audi's (2000) formulation of "secular reasons," and Amy Gutmann and Dennis Thompson's (2004) requirement of reasons "accessible to all the citizens to whom they are addressed" are all potential criteria when committees pronounce the (il)legitimacy – to borrow from Moore (2010a) – of certain reasons and arguments.

In this paper, I aim to contribute to a large and crucial project: determining how this process, of categorizing some reasons as legitimate and others as illegitimate, works in practice. I will present two institutions' distinct methods for constructing this legitimate–illegitimate divide: the method adopted by the UK's Human Fertilisation and Embryology Authority (HFEA), which I will argue seeks but fails to "balance" competing reasons, and the method of the US' American Society for Reproductive Medicine (ASRM), which I will argue seeks to "filter" out problematic reasons. In so doing, I will show that the HFEA and ASRM each resolve the practical tension of which reasons and arguments ought to influence decisions by constructing two very different legitimate–illegitimate divides.

2. Institutional missions and structures

Although both the HFEA and the ASRM play the most significant role in determining the rules for assisted reproductive technologies (ART) at the national level in their respective countries, they represent radically different conceptions of the governance of ART. Based on the recommendations of an appointed committee of inquiry chaired by British philosopher Mary Warnock, British politicians created the HFEA in 1990. During her chairmanship, Warnock argued in the *New Scientist*, "Increasingly and rightly, people who are not experts expect, as of right, to help determine what is or is not a tolerable society to live in" (as cited in Wilson, 2011). Reflecting this understanding, the HFEA was designed as a statutory body built upon deliberative democracy ideals of representing the range of public perspectives and social values in the deliberation of ART (Wilson, 2011). As a statutory body, the HFEA has the power to produce binding regulations based on this deliberation. The US, on the other hand, has avoided the implementation of federal regulations on ART, the only exception being a Centers for Disease Control and Prevention reporting requirement for "all fertility treatments in which both eggs and sperm are handled" (Centers for Disease Control and Prevention, n.d.). This leaves the ASRM, a professional self-regulating society founded by fertility experts in 1944, with the sole responsibility for designing guidelines for the use of ART. These guidelines, unlike the regulations of the HFEA, lack legal force. In spite of these significant differences, I define both as 'national deliberative ethics committees' for the purpose of this comparative project, on the grounds that each institution features central deliberative committees responsible for determining the most authoritative rules for ART in their respective societies.

The Human Fertilisation and Embryology Act of 1990 created the HFEA and assigned to it the responsibility of regulating the creation of embryos for use in treatment and research, the use of donated gametes and embryos, and the storage of gametes and embryos (Human Fertilisation and Embryology Authority [HFEA], 2009). It is composed of both a central deliberative committee and supporting staff. The chairman, deputy chairman and between one-third and one-half of the members of its deliberative committee (which I will refer to throughout as 'the HFEA' for ease) must be lay and unbiased. This 'lay and unbiased' requirement is operationalized as any person who has not been 1) a registered medical practitioner, 2) concerned with keeping or using gametes or embryos outside the body, or 3) concerned with commissioning, funding, or participating in research on keeping or using gametes or embryos outside the body (Department of Health (2008)). Most importantly, the HFEA carries out extensive public consultations when creating or reviewing policy, suggesting that it will in fact carefully consider public input. These consultations collect the views of members of the general public, patients, and other stakeholders through focus groups and an online comment period, after which the HFEA's support staff analyzes the data both quantitatively and qualitatively to provide an account that feeds into the HFEA's deliberations. This set of characteristics appeals directly to basic theories of deliberative democracy in attempting both to represent the range of ethical perspectives on issues and to bring into dialogue lay and professional perspectives.

As a self-regulating professional association, the ASRM serves a diverse membership of dues-paying professionals, including obstetrician/gynecologists, reproductive endocrinologists, and pediatricians. Its mission statement suggests that the ASRM only engages with the "lay public" in an educative role; there is no suggestion that the ASRM does or ought to accommodate what the general public thinks about the ethics of ART (American Society for Reproductive Medicine [ASRM], 2008). Unsurprisingly, then, there is no practice comparable to the HFEA's public consultation process.